Cáirde

Challenging ethinc minority health inequalities

The Experiences of Minority Ethnic Women Living with HIV

Reflections.

The research participants have brought their unique experiences and understanding to this project. They chose the images on this page and on the inside back cover from everyday magazines and publications and they added their own reflections to these images in order to provide the reader with a greater insight.

L'annee passé j'etais enceinte et mon enfant etais bien sauve, pendant la consultation prenatal.

Voila mon bebe qui est né en bonne sorte, cela veut dire qu'il est seronegatif.

Malgré ma seropositivité. Je reste objective, sportive et positive.

When thinking about being pregnant, I thought it can't work at all when I discover I am positive. But now I am very happy I have a baby and my baby is negative.

I came to know I was H.I.V. positive during pregnancy. I was so surprised and thought I will die the next day but with the medication-the anti-H.I.V. treatment today I can continue to live for many years.
99% of pregnant women give birth to healthy babies.

My first day when I was told I am H.I.V. positive I thought my life is finished.

Foreword

by **Mary Robinson**

This report is a timely and necessary wake-up call for Ireland to pay attention to the experience of women living with HIV in this country. Cáirde has enabled the voices of ethnic minority women living with HIV in Ireland to be heard on their own terms, a valuable and rare achievement. The sensitive and participatory methodology in this research has facilitated the inclusion of women who would otherwise be excluded, due to mistrust, language barriers or isolation. From a human rights perspective, it is ethically imperative that an affected community be strongly involved in any activities that impact it. This research is significant not only in its results and recommendations, but in the fact that ethnic minority women living with HIV have directed the process of identifying needs and developing responses. This report recognizes that women living with HIV are a powerful resource in tackling the disease in Ireland, as they are worldwide.

There are increasing parallels between women's experience of HIV and AIDS in Ireland and globally. In Ireland, 62% of new HIV infections in the first half of 2002 were among women, while 80% of these women contracted HIV through heterosexual contact. At the global level, of the 4.2 million adults newly infected with HIV in 2002, two million were women. Half of those living with HIV worldwide are women. In sub-Saharan Africa, where the participants in this study are from, 58% of those living with HIV are women, and by far the majority of HIV infections are due to heterosexual transmission. At the international level, UNAIDS has linked women's vulnerability to HIV infection to risk factors such as economic inequity, forced financial dependency, social exclusion and discrimination. Sadly, many of these problems are present in the lives of ethnic minority women in Ireland. These factors, which may have increased their risk of HIV infection, now make living with HIV more difficult. These women's experiences are evocatively described in the quantitative and qualitative findings of this research by the Women's Support and Development Group of Cáirde.

Worldwide, rural women often lack access to essential healthcare services or to the financial resources that would enable them to travel to clinics. In Ireland, specialized HIV clinics located in Dublin, Cork and Limerick are inaccessible to ethnic minority women living in rural towns, where they have been 'dispersed' by State policy. Most (92%) of the women are taking some form of medication, including anti-retroviral HIV drugs, in contrast to only 4% of people living with HIV in low and middle-income countries who have access to anti-retrovirals. At the Ethical Globalization Initiative, a non-governmental organization which I now lead, a key objective is to ensure that, worldwide, all who need them have access to these life-saving medicines.

Some of the women interviewed have problems discussing their HIV status with their partners, noting "he blames me for being HIV positive." A quarter feel that their HIV status causes problems for them socially: "people look at me differently because of my sickness." Similarly, in areas with high HIV infection levels, women are often blamed for bringing HIV to a relationship, and may be beaten or abandoned by partners when their status is discovered. HIV-related discrimination can undermine human rights, when denial of healthcare, job loss and social exclusion accompany a positive diagnosis. This report recommends counseling for individual and couples and training in partner communication around HIV. Communities must be sensitized to the experiences of those living with HIV. In addition to HIV-related stigma, nearly three quarters of these women have experienced some form of racism in Ireland: "Boys spit on me, throw stones at me at the road, throwing papers on me in the bus, calling me names like black, nigger and all that sorts." Racism also comes from service providers: "In the bus station a driver refused to let me get on the bus and swore at me after he let someone else on." As Cáirde suggests, an effective anti-racism code of practice must be put in place and adequate funding must be provided to challenge stereotypes and promote interculturalism in Irish society.

Cáirde

Challenging ethnic minority health inequalities

Foreword

At the global level, women are among the poorest of the poor, with access to the fewest resources and opportunities. They are frequently economically dependent on male partners.

In Ireland, 70% of women interviewed are financially dependent on social welfare, as their legal status does not allow them to work despite their desire to do so. For many, their legal status as asylum seekers or refugees is a major economic constraint and a constant source of worry. Financial dependency and limited resources prevent them from maintaining an adequate diet essential to their health, and limit their ability to provide nappies, clothes and food for their children. Global inequities and local economic dependencies must be challenged, and Cáirde recommends allowing asylum seekers to take up employment after six months in the asylum process, developing a mechanism to assess equivalence of qualifications gained overseas, and facilitating a gradual rather than sudden withdrawal of social welfare entitlements upon finding work, which will ease women's financial transition.

The process used by Cáirde has ensured that this marginalized group has space not just to identify problems but to generate solutions. Among the key areas highlighted for action, the report recommends amending the asylum process, by reintegrating asylum seekers into mainstream social welfare systems, reinstating women's access to private accommodation on medical grounds, and disseminating accessible information on legal rights to ethnic minority women. Broad-based policy reform and concrete assistance are needed in education and training, by allowing asylum seekers to take up FAS and State-funded training initiatives after six months, and providing childcare during training courses. In access to health services, the report recommends reviewing appointment systems at specialized HIV clinics, providing doctors with training regarding HIV and issues affecting ethnic minority women, and developing culturally appropriate sexual health materials with the participation of ethnic minority communities. This is particularly important, as within the study most women practiced safe sex, but 18% stated that they did not, leaving themselves open to re-infection or to passing on HIV to others.

This report calls for urgent action by hospitals, the Eastern Regional Health Authority, and government Departments, especially the Department of Justice, Equality and Law Reform. These institutions must take seriously their responsibilities to ethnic minority women living with HIV. Unlike many similar reports, that tend to demand more only of others, this research has been integrated by Cáirde into its own framework of action. The Women's Support and Development Group will meet regularly, providing a badly-needed safe space for ethnic minority women living with HIV to come together. The organization will provide information and leaflets on ethnic minority women's legal status and entitlements, employment, accommodation, protection from racism and discrimination, HIV testing and services for living with HIV. Cáirde will provide training to employment services, support organizations, churches and community based counselors on the experiences of women living with HIV, and link women to these services. An exciting exhibition is planned, where ethnic minority women living with HIV will bring their experiences to a wider audience. These efforts are to be applauded and emulated.

Much like our own approach at the Ethical Globalization Initiative (EGI), Cáirde is maximizing its impact by bringing the voices of those who are rarely heard to policy-makers and service providers. Only by doing this, and by ensuring that people living with HIV participate fully in planning and implementing the services and policies that impact their lives, can we hope for progress in tackling HIV and AIDS, in every country. I highly commend the excellent work of Cáirde and the women living with HIV who created this valuable report, and I hope that it will be widely read and acted upon.

With best wishes,

Mary Robinson

Listen

Table of Contents

Acknowledgements

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The Research participants did not want their identities to be known. Therefore, short abbreviations of their names are used and at their request, their faces are covered in the cover photograph. This is a stark reflection of the stigma and ongoing fears experienced by people living with HIV.

Acknowledgements:
A special thanks to the women who participated in the training and conducted the research themselves. We hope that this report can live up to their courage and bring about the changes so necessary. Also, many thanks to all the women who participated in the research by agreeing to be interviewed. We hope that this report does justice to the richness of their contributions. Also thanks to Elton John AIDS Foundation and Alternative Miss Ireland without whose support Cairde's work would not be possible.

Also, many thanks to all those who assisted by reading and making comments: Siobhan O'Donoghue (MRCI), Ruth Parkin (RIS), Cabrini Gibbons (IRC), Elva O'Callaghan (NCCRI), and Cairde staff team.

Part 1.Background to the Project

1.1 Introduction

This project was carried out through Cairde's Women's Support and Development Group (WS&DG) which is part of Cairde's **Women's Health Action** (WHA) programme.

Cairde is a non-governmental organisation working to reduce health inequalities among ethnic minorities; and is committed to supporting the participation of minority ethnic communities in enhancing their health.

Cairde operates two programmes to achieve its overall aim of positive health outcomes for all. **Healthwise Community Impact** (HCI) is an information and capacity-building programme which seeks to build the capacity of minority ethnic communities and organisations to respond to the health needs identified by their communities. **Women's Health Action** (WHA) is a programme which **aims** to enable women from minority ethnic communities to address health inequalities.

The **objectives** of WHA are:

- To support women from minority ethnic communities to identify their health needs.
- To build the capacity of women from minority ethnic communities to collectively address their health needs.
- To raise awareness of the issues affecting the health of women from minority ethnic communities.
- To support women from minority ethnic communities to influence policies which impact on their health.
- To support women from minority ethnic communities to build solidarity with other groups experiencing inequality.

The **core areas of work** of the Women's Health Action Programme are:

a) **outreach/advocacy work**: supporting minority ethnic women to address daily experiences in accommodation, education, welfare rights, immigration, asylum, work permits, health, racism etc.;

b) **development work and capacity building work**: establishing minority ethnic women 's groups/fora and providing a space for minority ethnic women to identify difficulties and experiences, and agree actions to address these difficulties together; and

c) **lobbying and policy development** to influence policies which impact directly on the lives of minority ethnic women .

1.2 Women's Support and Development Group

The Women's Support and Development Group (WS&DG) is one of the groups established by Women's Health Action to support minority ethnic women to identify their experiences and take action to address difficulties experienced on a daily basis. It was established in January 2002 for minority ethnic women living with HIV. Confidentiality is a critical factor in the group, and members are only introduced to the wider group after a period of building trust to participate in a group.

1.3 The Research Group

Membership of the Women's Support and Development Group at the time of the research was drawn exclusively from the African community living in and around Dublin. Participation in the research was open to all members of the Group, and a core group of 6-7 women actively participated in the research on an ongoing basis. This smaller subgroup, subsequently referred to as the research group, is the group of women who conducted the research. They were supported in the process by a development worker from the Cairde staff team and an external researcher.

Part 2.Introduction.

2.1 Introduction

Women living with HIV in Ireland are a silent and invisible group. Within this silent group are minority ethnic women living with HIV. Little is known among the general public or policy makers about their experiences, needs, desires and hopes. Cairde's Women's Support and Development Group has been together since January 2002. Members of this group are women who want to break that silence and tell their story; and the story of other minority ethnic women living with HIV in Ireland.

2.2 Why was this research needed?

Until recently, Ireland's experience of HIV disproportionately affected two main groups; gay men and drug users. Until 2000 (1) , trends in HIV positive diagnoses consistently showed that about 40% of people diagnosed with HIV were intravenous drug users, and about 20 - 25% were men who had sex with men. Consequently, services tended to develop in areas appropriate to the needs of these groups. For example, much of the community based HIV counselling services have developed as part of addiction counselling services, and community welfare and support services are often located in drug treatment clinics. Also, most of the research carried out to-date focused primarily on the needs of these groups. In the earlier period of HIV in Ireland, those being diagnosed with HIV were overwhelmingly men (2) and as such, services developed did not necessarily reflect the needs of women. The situation is now changing. Figures (3) show increasing numbers of women being infected with HIV through unprotected heterosexual sex with an infected partner. Women between the ages of 25-34 are now among the most at risk of infec tion from heterosexual sex.

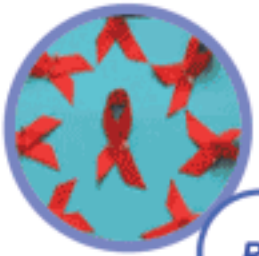
Also, the profile of new HIV diagnoses is changing. The number of minority ethnic women living with HIV in Ireland is growing (4). A healthier economy in recent times has led to Ireland experiencing inward migration instead of emigration, and this change in demographics is reflected in minority ethnic groups being among those being diagnosed with HIV. And so, minority ethnic women living with HIV in Ireland are linking with services which to-date have not been designed to take their specific needs into account. The needs and experiences of minority ethnic women living with HIV are complex. Their needs relate to their experience of HIV within their own families and communities, and in broader Irish society. Their needs also relate to their broader social and economic experiences in Ireland which affect their ability to access services, which in turn impacts on their health. The experiences and needs of minority ethnic women living with HIV in Ireland were not well documented in Ireland, nor indeed fully understood. Research among these women was needed to explore and identify their experiences and needs in more detail, in order to enable the better targeting of supports and services for this group. Based on the direct experiences of women participating in the Women's Support and Development Group and their friends, it emerged that this was a gap which needed to be filled; and minority ethnic women living with HIV should be at the centre of any effort to do this. The Women's Support and Development Group decided to initiate this research process which explored the needs of minority ethnic women living with HIV in Ireland. The purpose of the research was to provide a snapshot of the lives and experiences of minority ethnic

(1) National Disease Surveillance Centre (NDSC) Reports 2000-2002. See Appendix 1 for NDSC Statistics.

(2) NDSC Reports 1998-2002. See Appendix 1.

(3) NDSC Reports 1998-2002. See Appendix 1.

(4) NDSC Figures for Quarters 1 and 2 of 2002 show that of the 110 new diagnoses through heterosexu al contact, 80 (73%) were born in Sub-Saharan Africa, of whom 62 (77%) were women. This figure is dependent on patterns of testing and reporting.



women living with HIV in Ireland. The objectives of the research were agreed as follows:

- To identify the experiences of HIV positive women from a range of cultural backgrounds living in Ireland in accessing health services, education, training, accommodation, asylum and employment;
- To identify the barriers facing women in accessing health services, education, training, accommodation, asylum and employment;
- To identify actions and supports to overcome such barriers.
- To relate the experiences and issues identified to the policy context within which the women live.

2.3 How was the research done?

From the outset, minority ethnic women living with HIV were at the centre of this research. With the assistance of a grant from the Combat Poverty Agency, Cairde engaged an external researcher familiar with the use of participatory action research who worked with a core group of women who were active members of the Women's Support and Development Group. A key part of the research was to build the skills of the core group to carry out as much of the research as possible themselves. A number of training objectives were agreed:

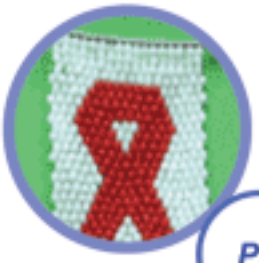
- To train a core group of women in gathering primary data, including designing questionnaires, designing interview questions, and focus group discussion questions;
- To develop the women's capacity to conduct interviews and focus group discussions;
- To develop the women's capacity to analyse data collected;
- To develop strategies for action with the women based on the data collected.

This training component, together with the research objectives, meant the research was a participative project.

In addition, Cairde secured a grant from Dublin Inner City Partnership for the Women's Support and Development Group to take part in social analysis skills training. This training programme explored gender and sexism, racism and discrimination, and power and oppression. This programme helped the participants to link issues emerging in the research with wider contextual factors. The training and research was carried out voluntarily by a core group of women who were members of the Women's Support and Development Group. Not all of the members of the group wished to take part. The research project was facilitated by Cairde through weekly meetings between the researcher and the participating women from September 2002 to April 2003. Childcare, transport, lunch and additional expenses were provided.

2.4 The Research Framework

In the early stages, the researcher and the research group explored the experiences of their peers in the Women's Support and Development Group, and the policies which impacted on their lives. A number of key areas were identified in the life experiences of minority ethnic women living with HIV in Ireland. The Model of a Wheel of Life was used as a framework to ensure that the full impact of living with HIV would be explored. The Wheel was adapted to identify all the different aspects of the women's lives. Legal status in Ireland emerged as being a very important key to many opportunities. The women were clear that their positive HIV status and their ethnic origin affected all aspects of their lives.



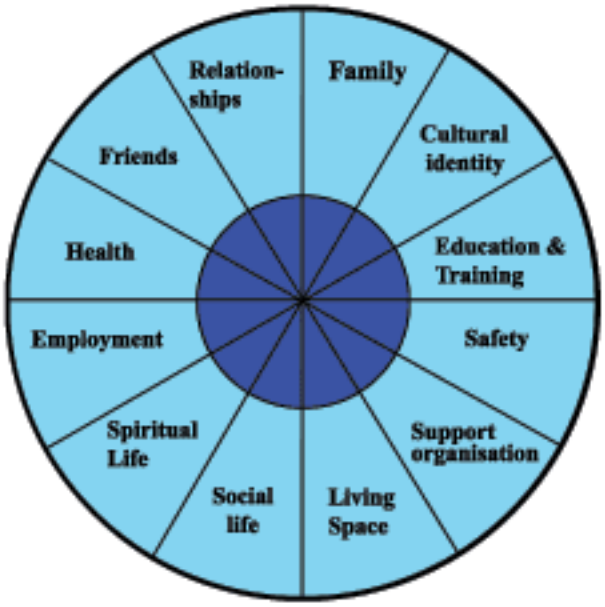


Chart1. The Wheel of Life

Once the Wheel of Life was adapted to reflect their lives, a series of key questions were developed exploring each aspect of their lives (See Appendix 2).

2.5 Choosing One-to-One Interviews

The method of asking the key questions was given considerable consideration. Each of the participating women had experienced stigma and discrimination as a result of living with HIV. Therefore, there were many concerns about confidentiality, and all of the women wanted to select a method they were comfort able with. Roundtable meetings, informal conversations and formal interviews were all considered as options. The final decision was to conduct one-to-one interviews using key questions set out in questionnaire format to guide the interview process.

The participating women practiced their interview skills on one another, and developed a detailed questionnaire using the key questions to ensure that the interviews would be the same. There was no space for interviewees' names on the questionnaire to ensure anonymity and confidentiality. The questionnaire was translated into French by, and for, the women who were more comfortable speaking French. (See Appendix 2 for the Questionnaire in English)

2.6 Analysing the Issues

Once all the interviews had been completed (49 in total), the research group then discussed the issues emerging section by section; and related the issues to their own experiences and the wider policy context. The data presented in this report is both quantitative and qualitative. It reflects both the answers from the interviews as well as the discussions and reflections of the research group on the findings of the interviews. The research group functioned as an ongoing focus group, where the issues emerging from the interviews were discussed and explored in more depth on an ongoing basis throughout the research process.

2.7 When was the research done?

Table 1: Timetable of Research

September-October 2002	Developed the Wheel of Life and key questions.
November 2002	Interview skills training.
December 2002	Women undertook their first pilot interview & interview amended.
January - February 2003	49 interviews were undertaken. Social Analysis Skills Training.
February - March 2003	Inputted data.
March - April 2003	Women discussed and analysed information section by section. Discussed and prioritised recommendations and actions.
May - June 2003	Researcher compiled draft report. Report finalised by women and Cairde.

2.8 How were the women interviewed selected?

Identifying women to interview was a challenging process for the research group. Confidentiality and trust were critical in this process. Due to the stigma and discrimination experienced by people living with HIV, there aren't many minority ethnic women who feel they can readily disclose their HIV positive diagnosis. It was therefore a personal risk for the interviewee to do so. Similarly, it was a personal risk for the interviewer to ask another woman to participate in the research as, given that it was a participatory research process, this also involved disclosing their own HIV positive diagnosis. The process of locating women to be interviewed was therefore a slow and complex one led by the research group.

Members of the research group initially interviewed other women whose HIV status was already known to them as acquaintances or friends. These interviewees in turn directed the women to other interviewees. The number of women interviewed grew in this way. The research group also located potential interviewees using their own attendance at the various specialist clinics in Dublin as a guide. Once a potential participant had been identified, it took the women time to build up a sufficient level of trust and confidence before they could broach the subject of the research and the interview. Where the interviewer was not comfortable that a sufficient level of trust was established the interview and the research were never mentioned.

As part of the interview process a small allowance was provided to enable the interviewer to invite the interviewee for 'coffee and a cake' in a coffee shop. This was useful in that it ensured that the interview was conducted in an environment which would not require either woman to explain what they were doing, as might be the case at home or in another venue.

HIV was not specifically written on the questionnaire. However, as it was a participative process, the interviewers explained to each woman they interviewed that women living with HIV were conducting research among other women living with HIV. Both women, therefore, disclosed their HIV positive diagnosis and understood that only

women living with HIV were being included in the research. The research group was more comfortable with this as it protected both the interviewer and the interviewee. Interruptions in the interview process by someone else, or the questionnaire being seen at home or by friends would not indicate that either woman was HIV positive.

The research group had a lot of concerns about how to approach other positive women (women diagnosed HIV positive) to ask them to participate in the research. Initially, each member of the research group agreed to do one interview to see how they got on with the process. These initial interviews proved to be the most difficult for all of the women. All, however, did one interview and collectively the group discussed their experiences and reviewed the responses. The questionnaire was revised and a number of changes/improvements were made. The research group decided to conduct the interviews on an interview by interview basis, with each woman being advised to only conduct interviews they felt comfortable with.

Part 3.The lives of Minority Ethnic

3.1 Introduction

Minority ethnic women living with HIV do not live in a vacuum. As set out in the Wheel of Life, different aspects of women's lives impact on each other. This is also the case when looking at the wider issues which impact on the lives of women. Many laws, policies and procedures put into place by government agencies and bodies impact directly on minority ethnic women living with HIV.

3.2 Policies which affect Women in the Study

3.2.1 Legal Status

The research group reflected in some detail the different things that affect their day-to-day lives, and agreed that the one of the most fundamental issues for them is their legal status in Ireland. A woman's legal status affects her ability to access services, to choose where to live, to work, to access further education and training, and indeed social welfare entitlements. A woman's legal status affects many other aspects of her life, not least of which is whether or not she will have a future in Ireland. Some of the different situations are set out below.

3.2.1.1 Refugee Status

A refugee is a person who is forced to leave her country due to a well founded fear of persecution, and who is unable to return to her own country for reasons related to her race, religion, nationality, membership of a particular social groups or political opinion. There are two categories of refugees.

'Programme' refugees are people who have been invited to Ireland by the Irish government in response to requests from bodies such as the UNHCR (e.g. Bosnians 1992-97).

'Convention' refugees are people who have been granted refugee status by the Irish government under the 1951 Geneva Convention thereby recognising their well founded fear of persecution in their home country.

Programme refugees can apply for citizenship after three years, while convention refugees can apply as soon as they are recognised as a refugee. Ireland has a legal responsibility to accept applications for refugee status, to determine who is a refugee and to extend the necessary protection to such a person once refugee status is granted. Once a woman is granted refugee status by the Irish state she has all the same rights and entitlements as an Irish woman.

3.2.1.2 Asylum Seekers

An asylum seeker is a person who has applied to the Irish government to be recognised as a refugee under the 1951 Geneva Convention. They have a legal entitlement to stay in Ireland while an application for refugee status is being processed. Asylum seekers generally have limited rights, but some are more affected by policy changes in recent months and years. Asylum seekers rights and entitlements are dependent upon the date when their application for asylum was made. When policies change, only those making applications after those changes are affected. Initially asylum seekers were catered for under the social and supplementary welfare systems. However, since April 2000, asylum-seekers have been accommodated under a scheme of Dispersal and Direct Provision. Under Dispersal and Direct Provision, asylum seekers are accommodated for approximately two weeks in a reception centre in Dublin when they arrive. During this period they have the option to undergo voluntary health checks (including a HIV test) with around 75%(5) uptake. They are then 'dispersed' to an accommodation centre outside Dublin. Asylum seekers are accommodated on a full board basis which means meals are provided. They receive €19.10 per adult and €9.60 per child per week plus child benefit. Until recently, some asylum seekers had been allowed to leave the Dispersal and Direct Provision scheme to move into mainstream social welfare provision and private accommodation if their circumstances deemed it necessary,

(5) Reception and Integration Agency

usually on medical grounds. However, since April 2003 this is no longer the case. Now, all asylum seekers are accommodated within Dispersal and Direct Provision managed entirely by the Department of Justice through the Reception and Integration Agency. Asylum seekers are not allowed to work, or study, and are not entitled to social or supplementary welfare.

3.2.1.3 Leave to Remain

Where a woman's application for refugee status has been rejected under the 1951 Geneva Convention, and her appeal of that decision has also been rejected, she can then apply to be granted leave to remain in Ireland. This leave is granted on a discretionary basis by the Minister for Justice, and considers factors such as family circumstances and humanitarian issues. However, the reasons for refusal do not have to be given. If a woman is granted leave to remain she has the same rights as a refugee in Ireland.

3.2.1.4 Migrant Workers

Some minority ethnic women are living and working in Ireland in one of two ways; either with a work permit or with a working visa. All people who are from non European Economic Area countries require a work permit or working visa before they can take up employment here.

Working visas are issued to workers in certain high skilled and technical professions when an offer of employment in Ireland has been made. They are usually valid for two years, and the worker free to seek employment with another employment within that time period if she/he chooses.

Work permit applications are applied for by the employer at a cost of approx €500 and are processed by the Dept of Enterprise, Trade and Employment. Work permit applications are only accepted when the worker is outside the country (except for renewals), and they are generally valid for one year. Permits are issued directly to the employer which places the employee in a dependent relationship with the employer. The work permit only grants the woman the right to work in the agreed position with that specific employer. Being granted a work permit has become increasingly difficult in Ireland with the recent downturn in the Irish economy, and there is currently a bar on applications for certain sectors.

Women with work permits or working visas have their passports stamped by the Garda National Immigration Bureau to correlate with the dates of the employment offered. While in employment they are entitled to social benefits linked to PRSI contributions.

If an employer terminates the employment within the one year period of the work permit, women are entitled to social and supplementary welfare as long as the stamp on their passport is still valid. However, many women experience difficulty accessing social benefit payments. It is a requirement to register with FAS in order to receive social welfare, and some have experienced difficulty registering with FAS as they are generally not entitled to access FAS employment services. Therefore, they experience difficulty accessing the social benefit to which they are entitled.

If an employer can not, or will not, renew a work permit at the end of the year when the stamp on their passport is expired, women are in a difficult situation. They are not entitled to social benefit or supplementary welfare upon losing their work despite having paid PRSI contributions, because their legal entitlement to remain in Ireland has expired. There is no period of grace to facilitate accessing social benefits. Migrant workers on work permits are means tested to assess eligibility for medical cards.

3.2.1.5 Spouses of Migrant Workers

Some women are in Ireland with their husbands who are working with a working visa or permit. In this situation, wives are dependents of their husbands and are not entitled to take up employment (the same applies to men if their wives hold the permit). Dependents are not entitled to state provided training courses, and are assessed for social or supplementary welfare on the basis of the assessment as a couple. Their medical card entitlement is means tested. Their ability to access social benefit in the event of their husband losing his job or the work permit not being renewed is similar to the circumstances of migrant workers described above. In more recent months, dependents of migrant workers with permits in certain sectors (e.g. nursing) are entitled to change their own status from dependent to a work permit on their own right if they have a willing employer.

3.2.1.6 Students

Women from outside Ireland are entitled to come to Ireland to study provided that they can prove that they have been accepted for a recognised programme of study, and have the necessary funds to support themselves. They may or may not require a visa depending on their country of origin. In most cases they are entitled to work up to 20 hours per week, but are not entitled to social or supplementary welfare. Women on student visas are not entitled to medical cards, and are sometimes required to prove that they have private medical insurance.

3.2.1.7 Wives of Irish Citizens

If a woman from a non EU country married an Irish citizen prior to 30 November 2002 she may be entitled to citizenship in certain circumstances after three years of marriage. A woman who married an Irish citizen after this date can only apply for citizenship through the naturalisation process. This means fulfilling certain conditions including residing in the State for at least three years and being of good character. Citizenship grants a woman all the same rights and entitlements as an Irish woman.

3.2.1.8 Residents (Mothers of Irish citizens/Irish born children)

Many women have in the past been granted residency on the basis of being the mother of an Irish born child. As a resident, a woman is entitled to work, social and supplementary welfare, and to a medical card provided she meets the necessary income threshold limits. From 1990 up until early 2003, non Irish women who had children born in Ireland were generally granted residency in Ireland. In 2001, 3,153 people were granted residency on the basis of being parents of Irish-born children. In 2002 this increased to 4,027, of which 3,077 were people who had been or were in the asylum process, and 950 were non-EU migrant workers or students(6) .A Supreme Court ruling in January 2003 changed this situation, which made it clear that non-EU parents of Irish children are not automatically entitled to residency in Ireland. From February 2003, non-EU immigrants are allowed to apply for leave to remain in the State on humanitarian grounds, including parentage of children born here, but not until they receive a deportation letter. Applications will be decided on an individual case by case basis, and all factors will be taken into account in the decision, including the length of time in the State. This may affect the 11,000 outstanding applications from parents of children born as far back as September 2001. Those with outstanding asylum applications will have their residency applications returned, as the Department of Justice has indicated that having both an application for asylum and a residency application as a parent of an Irish born child is no longer possible. For those whose applications will not be returned, applications for residency as parents of an Irish born child will be assessed on a case by case basis. In the event of asylum applications being rejected, asylum seekers will be entitled to apply for leave to remain citing parentage of an Irish born child as grounds for leave to remain.

(6) The Irish Times 02/09/03

3.2.1.9 Women Who May be Undocumented

There is also an unknown number of women who are not in any of the situations described above, who may be undocumented living in Ireland. It is estimated that 10% of migrant workers are undocumented, many of whom are women(7). Most undocumented people have come to Ireland through legal means, but through a variety of circumstances end up without documentation. Their situation is the most precarious as they are not entitled to any services in the state, and may be particularly reluctant to link with any agencies or services.

3.2.2 Access to Services

A woman's legal status is the key to accessing all services in Ireland. Women who have been granted refugee status, residency or leave to remain merely have to comply with the same regulations as Irish women in order to qualify for services. Asylum seekers access services through the provisions of the Dispersal and Direct Provision system. However, the situation is less clear for women on work permits or working visas, students and women living in Ireland undocumented. For women in the less clear situation, accessing services appears to be on a more ad hoc basis, often depending on the discretion of service providers. A definitive outline of entitlement to services proved difficult to determine, as indicated in the next section.

3.2.2.1 Health Care/Services

Free public health care is means tested in Ireland, with medical cards issued to those on lower incomes(8) . **At the end of 2001 there were about 1.2 million people (30% of the population) covered by a medical card (NESF 2002). Women granted refugee status, residency or leave to remain merely have to comply with the same regulations as Irish women. However, the situation is less clear for women on work permits or working visas and students. In some circumstance women have been obliged to prove that they have private medical insurance for visas to be renewed in order to not incur cost to the public system. However, others without private cover have accessed hospital care at the discretion of hospital staff. It is assumed that all women would be entitled to access health services through hospital in emergency situations, however determining a definitive entitlement proved difficult. Maternity care is provided free to all women legally resident in Ireland. If a woman is undocumented she has no right to free maternity care. She is entitled to access care in exchange for payment, and this is negotiated with individual hospitals. However, in emergency cases it is assumed that women would be provided with care and issues relating to cost addressed at a later date.**

3.2.2.2 HIV Treatment and Medication

Access to HIV testing, treatment and medication is not means tested in Ireland, and is free to all who need it at specialist clinics in certain public hospitals. The specialist clinics are located in the major urban centres of Dublin, Cork and Limerick. This poses problems for many minority ethnic women living with HIV, particularly asylum seekers within the Dispersal and Direct Provision scheme, who find themselves located a substantial distance from these specialist clinics. Until recently, women were allowed to be moved out of the Dispersal and Direct Provision system if a medical condition required this, but this is no longer automatically the case. Also, there have been some isolated incidents where women were refused treatment when their legal status was unclear to health service providers.

(7) Source: Migrant Rights Centre, Dublin

(8) The income threshold varies depending on circumstances but in general a married couple receives a medical card on an income below €200 and a single person living alone receives a medical card with an income below €138.

3.2.2.3 Social and Supplementary Welfare

Women who have been granted refugee status, res idency or leave to remain merely have to comply with the same regulations as Irish women in order to qualify for unemployment allowances and social welfare payments. Asylum seekers are not entitled to social and supplementary welfare. As mentioned earlier, accessing social benefits may be problematical for migrant workers. If an employer terminates the employment within the one year period of the work permit, women are entitled to social and supplementary welfare as long as the stamp on their passport is still valid; but may experience difficulty due to compulsory registration with FAS. However, if an employer terminates employment at the end of the year when the stamp on their passport is expired, women are not entitled to social benefit, despite having paid PRSI contributions, because their legal entitlement to remain in Ireland has expired (See Section 3.2.1.4.).

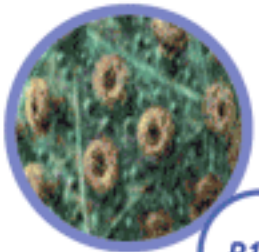
Students are not generally entitled to social welfare payments, however in some instances supplementary welfare may be paid. Those living in Ireland undocumented are not entitled to any allowances or payments. Overall, much entitlement appears to be at the discretion of community welfare officers depending on the individual circumstances of the woman.

3.2.2.4 Legal Services

Asylum seekers are entitled to free legal representation in asylum issues provided through the Refugee Legal Service. For criminal matters, all women are entitled free legal aid if they can show that they do not have the means to pay legal fees.

3.3 What Were the Women's Experiences?

This section sets out the various responses to the questions asked in the interview exploring each important aspect of the women's lives according to the Wheel of Life described earlier (see Appendix 2 for a copy of the interview questions). This section also contains some details of the ongoing reflections of the research group on the findings. Analysis of issues emerging from these responses is set out in Part 4.



3.3.1 The Women Interviewed

- 49 women were interviewed. All were from Africa; there were thirteen different nationalities involved in the research.
- 41 (84%) interviews were conducted in English; the remaining 8 (16%) were conducted in French.

Table 2. Nationalities of the Women Interviewed

Nationality	No. of Interviewees	Nationality	No. of Interviewees
South African	12	Angolan	2
Nigerian	9	Cameroonian	1
Congolese	9	Kenyan	1
Zimbabwean	4	Malawian	1
Senegalese	3	Tanzanian	1
Ivory Coast	2	Zairian	1
Lesotho	2	Unknown	1

- The legal status of the women interviewed was unclear. Many of the women interviewed were unsure of their legal status. It is possible that some of those who identified themselves as refugees were, in terms of legal status, asylum seekers.

Table 3 Legal Status of the Women Interviewed

Legal Status (where known)	% of Interviewees
Asylum seekers	39% - 19 women
Refugees	27% - 13 women
Residents	18% - 9 women
Leave to Remain	2% - 1 woman
Student	2% - 1 woman
Work Permit	2% - 1 woman
Married to an Irish Citizen	2% - 1 woman
Unknown	8% - 4 women

The age range of the women interviewed was between 20 and 42 years; the average age of the interviewees was 31 years.

- None of the women interviewed had been in Ireland longer than seven years. 80% of the women had been in the country less than three years. The average length of time in Ireland was just over two years.
- Over half of the women interviewed (60%) had children with them in Ireland.
- Just over half of the women (51%) had a husband/partner.

The research group reviewed the profile of the women they interviewed in some detail and felt that their profile was a reasonably accurate reflection of their own lives and experiences as African women living with HIV in Ireland.

3.3.2 Reasons for Coming to Ireland

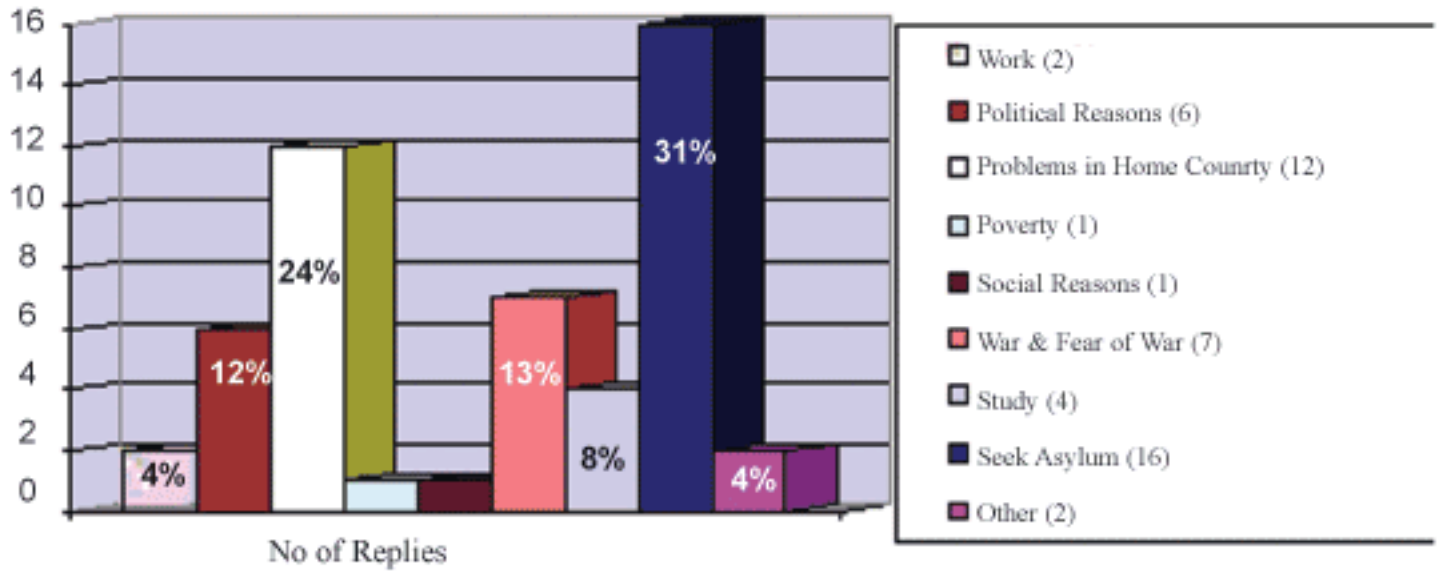


Chart 2. Reasons for coming to Ireland·

A combined total of 49% of replies showed the reasons for coming to Ireland were due to difficulties in other countries including political reasons (12%), problems in their home country (24%) and war/fear of war (13%); while a further 31% of replies were to seek asylum.

'…fear of being attacked by the people who killed my child's father'
'…. I was raped, assaulted and kicked there and had to leave'

' …because of my husband's death, they killed him so they wanted to kill me'

"….je suis en Irlande suite aux problemes politiques dans mon pays'

The reasons why the women interviewed came to Ireland reflected the breadth of reasons within the research group.

3.3.3 Activity Since Coming to Ireland

• The majority of the women (48%) had being doing "nothing "(9) since they arrived in Ireland. These women explained that their status as asylum seekers prohibited them from working.

Table 4. Activities since Arrival in Ireland

Activities since in Ireland	No of Replies	% of Total
"Nothing"	24	48%
Studying	10	20%
Working	14	28%
Other (child bearing/sickness)¥	2	4%

¥ Some people gave more than one answer so the total is larger than the sample size

3.3.4 Accommodation

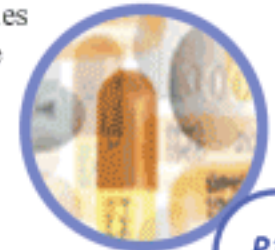
86% of the women interviewed lived in Dublin when they first arrived in Ireland. 71% of these women still lived in Dublin, while 12% of the remaining women lived in the surrounding counties of Louth, Meath, Kildare and Wicklow
The women lived in a variety of different types of accommodation, as can be seen in the Table 4 below.

Type of Accommodation	No of Respondents	% of Respondents
Private Rented Accommodation	27	55%
Room in Shared House/Apartment	11	22%
Hostel	7	14%
B & B	1	2.5%
Public Housing	1	2.5%
Unknown	2	4%

Table 5. The Types of Accommodation the Women live in.

Over half of the women interviewed who expressed an opinion (57%), stated that they were happy with their current accommodation, mainly due to the fact that they were in private rented accommodation and did not have to share in hostel accommodation. Of those who were unhappy, the main reasons for this were lack of privacy in having to share their space and facilities with others; the space being too small and being located in a disadvantaged area.

The concept of communal living, a general feeling of being more vulnerable to infections as women living with HIV, and limited access to cooking facilities were issues highlighted in the research group's own discussions on these research findings.



(9) This was an open-ended question; the women used this term themselves.

3.3.5 Safety in Ireland

· The vast majority of the women (92%) felt safe living in Ireland, particularly those who have experienced war and other problems in their own countries.

' it is much better here (in Ireland) than in my own country in so many things… in my country people are robbing money, hijacking, raping and shooting others'.

· Nearly three-quarters of the women-40 women (69%) had experienced some form of racism in Ireland.

Table 6. Different Types of Racism Experienced

Types of Racism Experienced	No of Respondents
Name Calling on the Street	17
Name Calling at service providers by other customers	6
Name calling by Service Providers	2
Physical assault	4
Refusal of services	2
Rude services by Service Providers	2
Customer refused to be served by me	1
Refused to sit beside me on the bus	2
Various Incidents (not specified)	4

The women interviewed described these incidents in some detail:

'Boys spit on me, throw stones at me at the road, throwing papers on me in the bus, calling me names like black, nigger and all that sorts'.

'They used to touch me when I first came and feel my skin and ask me if I had a tail'

'One day I went to the social welfare and someone wanted to skip the queue and was shouting saying all these monkeys are just coming here for the money'.

'In the bus station a driver refused to let me get on the bus and swore at me after he let someone else on'.

The women in the research group indicated that experiences of racism caused significant levels of distress and feelings of powerlessness.

3.3.6 Family Circumstances

About half of the women (51%) had children. Two women had to leave their children in their home country because they did not have the necessary visas.

51% of the women had husbands/partners.
Very few of the women (4%) had other family (a brother or sister) in Ireland.

For those women bringing up children in Ireland, a lack of family support was a problem. Some of the women also felt that there was a lack of discipline and respect among children in Ireland, and this made parenting more difficult in Ireland.

36% of the women who had children had no child-care support. As one woman described it…

'it is very difficult, most of the time I cry with my baby, when I have to push the buggy and go every where in the cold with a small child….'

Table 7. Childcare Arrangements

Where the Women get Childcare Support	% of women who have children
None	36
Husband	24
Boyfriend	4
Friends	12
Family	4
Other organisations	8
Unknown	12

The majority of the women in the research group had small children and lack of access to childcare or indeed any form of external support had caused them significant stress particularly in relation to attending the hospital clinics.

3.3.7 Employment and Money

About half of the women stated that they had been doing "nothing" since they arrived in Ireland, explaining that they were not entitled to work.
20% of the women had done some study since coming to Ireland, while 29% had worked for a period while they were here.
Only 10% of the women were currently working, three on a part-time basis and two on a full time basis.

Table 8. Length of Current Employment

Length of Current Employment	No of Women
2 years	2
1 year	1
< 6 months	2

Of those who were currently working, 60% (3) liked their job (it was not stressful) and 40% (2) did not like their job. These women did not like their jobs because they were "not well paid" and were "not good jobs".

The majority of the women interviewed had good employment skills, transferable to the Irish context, as can be seen in the table below.

Table 9. Main Occupations/Professions of the Women Interviewed

Occupations	No. of Women	Occupations	No of Women
Accountant	1	Office Administrator	2
Beautician	3	Receptionist	3
Bank Cashier	2	Sales	5
Chef	2	Secretary	3
General Worker	1	Self-employed	1
Hairdresser	1	Student	11
Home maker	1	Teacher	2
Nurse	1	Unemployed	2

18% of the women were actively seeking work.
22% of the women indicated that they were not allowed to seek work because of their status as asylum seekers which did not allow them to work.
The current health status of a small number of the women (at least 4%) effectively prohibited them seeking employment.
At least 70% of the women were dependent on social welfare for their income. Financial survival was a constant struggle for all the women.These circumstances were similar to those of the research group, who indicated that coping was as an ongoing battle, particularly where the women had children to clothe and feed. Maintaining a healthy diet on a limited income was also a challenge for the women in the group who saw a good diet as an important strategy for staying well. The majority of the women in the group were not allowed to work given their status as asylum seekers. For the small minority of those who could work, the absence of stepping stones, adequate and affordable childcare and a mechanism for the gradual withdrawal of social welfare payments made it very difficult for them to find suitable employment

3.3.8 Education and Training

• 37% of the women had some form of third level education, while 50% had completed secondary level and 13% had completed their education to primary level.

• 44% of the women had qualifications that were usable in Ireland, 51% women had qualifications that were not usable, while 5% did not know whether or not their qualification was usable.

• The main reason given for unusable qualifications was the fact that the qualification given in the women's home country was not recognised in Ireland.

• 12% of the women were currently studying to gain a qualification that would be usable in Ireland. One woman was undertaking a FAS course while four of the women were attending a private college. These women were studying computers and/or business.

• 78%of the women said they would like to do further studies/training.

Many of the women in the research group had skills that they would have liked to have been able to use but for various different reasons were unable to. For example, one woman had been advised that she would need to retrain since her current occupation within the healthcare profession was considered too 'high a risk'.

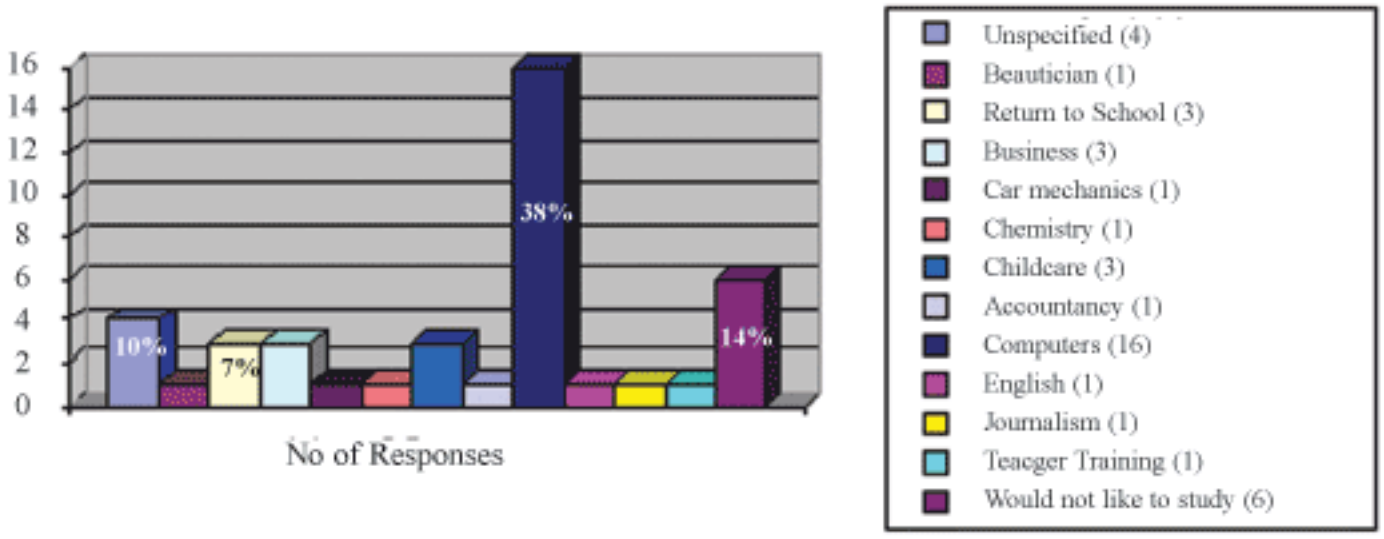
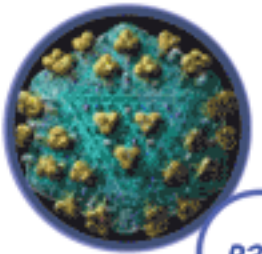


Chart 3. Types of Training the Women would like to Undertake



3.3.9 Health and Health Services

Well over half of the women (61%) said they did not feel healthy, while 39% said they were generally healthy.

GP Visits

35% of the women visited their doctor monthly, 37% of the women occasionally, and 14% of the women never visited their doctor.

Check-ups

37% of the women had occasional check ups, 27% had monthly checkups, while 12% of the women never have check ups.

Medication

92% of the women took some form of medication. The types of medication taken by the women included a range of anti-retroviral and combination therapies, anti-depressants and TB medication. Products named includ Combivir and Nevirapine.

37% of the women said they had no problems taking (HIV) medication.

'….the tablets are my life' said one women

14% of the women had problems when they started taking the medication.

'It makes me feel drowsy and dizzy sometimes'

12% of the women indicated that HIV medication made them feel sick on an ongoing basis.

Attendance at Specialised Clinics

41% of the women attended the specialised clinics in the hospitals quarterly, monthly or fortnightly while 18% attended only occasionally.

Attending the clinics was complicated for the women in terms of physically getting to the hospital and in relation to the amount of the time spent waiting for an appointment. This caused the women problems both in relation to childcare and time off from work for those who were working. It was not unusual for the women to spend many hours in the hospital clinic waiting to be seen.

A significant majority (82%) of the women were happy with the health service, praising the level of confidentiality within the service. The majority of problems identified related back to the issue of appointments and time-keeping for appointments.

The majority of the women in the research group took HIV medication with many of them having had difficulties with it, particularly in the early stages when it made them really ill. At the time of the research, the entire research group commented on the discipline required to take the medication at the required regular intervals. This posed challenges for them, particularly in communal accommodation when the majority of medications require refrigeration. It was also highlighted that women who do not speak English experience difficulty.

3.3.10 Relationships

A significant number of the women (78%) were in a relationship at the time of the interview, with well over half of these women (66%) in relationships of longer than one year

Table 10. Types of Relationships

Types of Relationships	No of Women	As a % of Women in Relationships
Marriage	15	42%
Long-Term Partner	10	28%
Boyfriend	11	31%

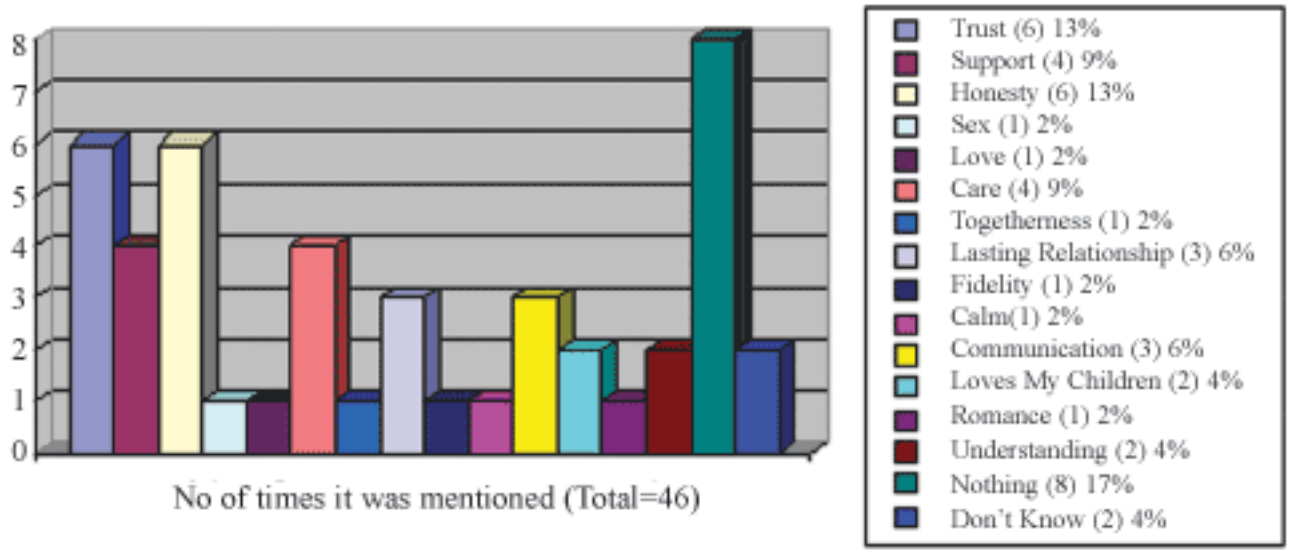


Chart 4. Aspects the Women liked about their Relationship

Trust, honesty and care were the three characteristics most frequently identified by the women as positive aspects of their relationships. A number of women (16%) indicated that there was "nothing" they liked about their relationship.

18% of the women associated their HIV status with something they disliked in their relationship.

He.... 'blames me for being HIV positive'

80% of the women stated they were fully open and honest with their partner.

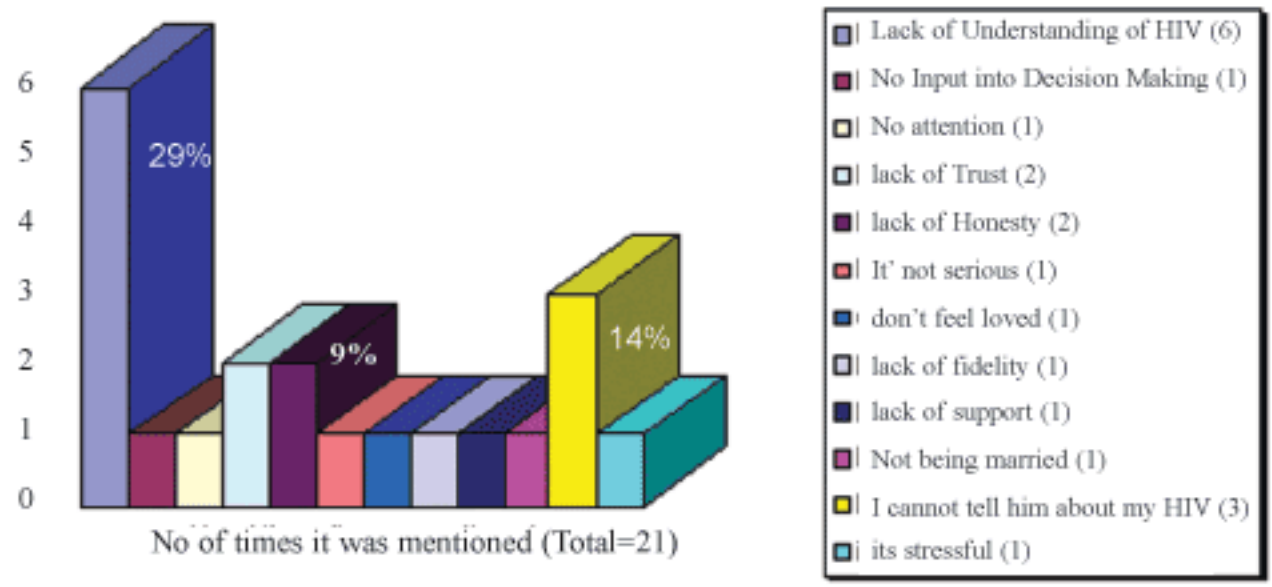


Chart 5. Aspects the Women disliked about their Relationship

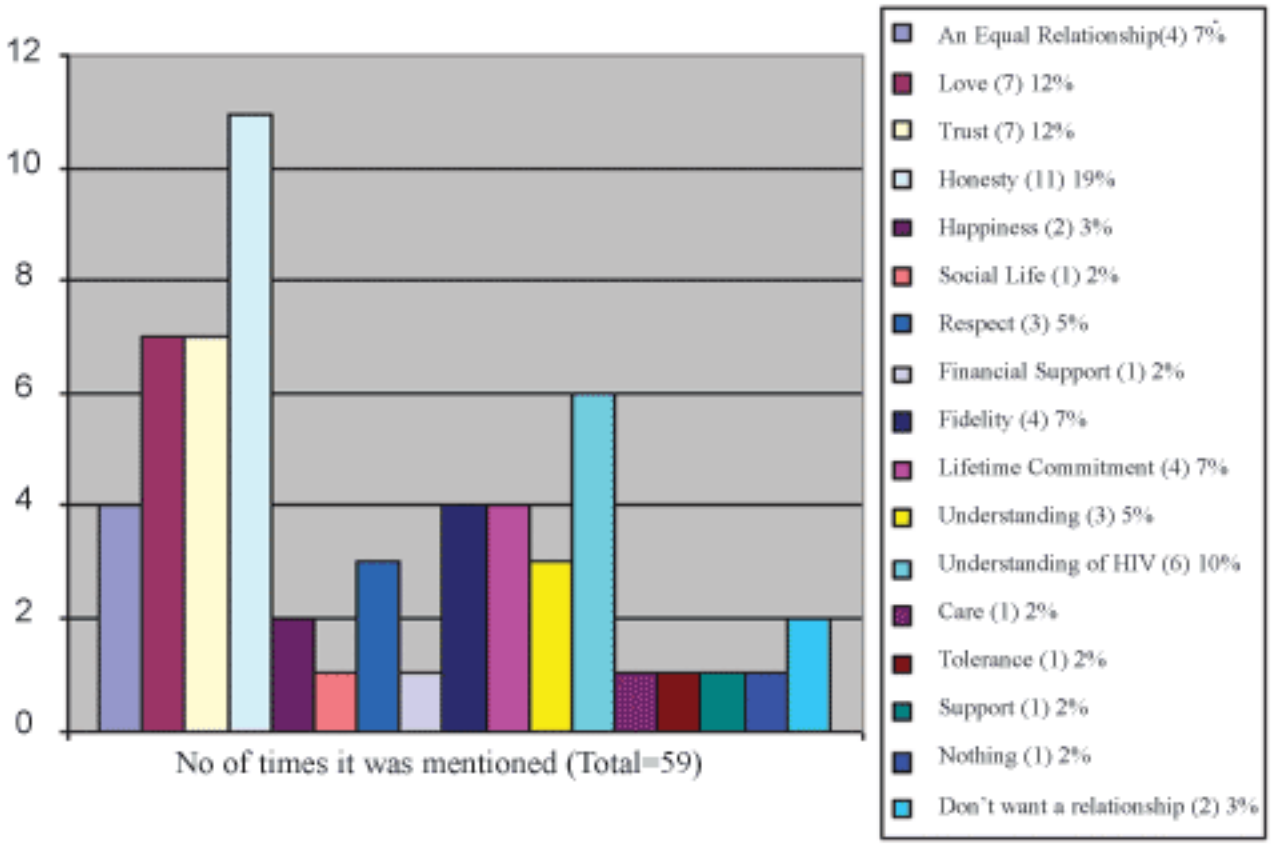


Chart 6. What the Women wanted from a Relationship

• 51% of the women interviewed said they were sexually active, 32% were not sexually active and the remaining 17% declined to answer this question.

• 76% of the women stated they did/they would practice safe sex. 18% said they did not while 6% of the women did not respond.

Disclosure of her positive HIV status was the most difficult thing for most of the women in the research group and it was something that many of them had grappled with, often experiencing very negative responses or rejection from partners.

3.3.11 Social Life

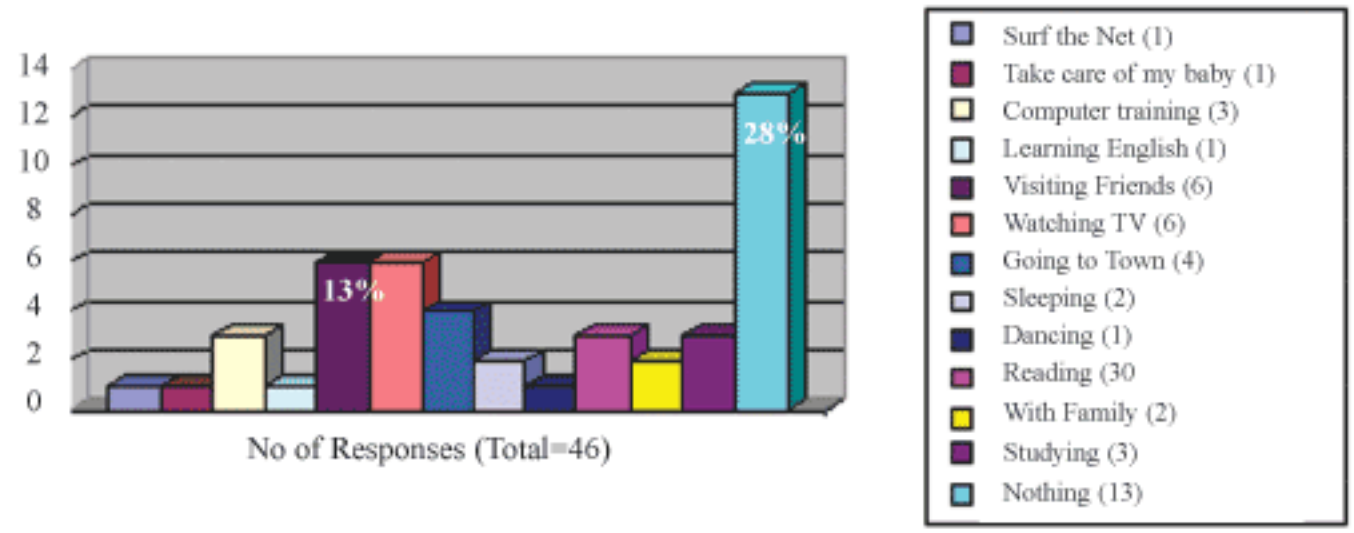


Chart 7. What the Women liked /would like to do in their Spare Time

• 90 % of the spare time activities of the women involved little or no cost.

• 33% of the women had friends in Ireland. The women met, and made, friends in various different ways, as seen below, but most met their friends in hostels and at hospitals

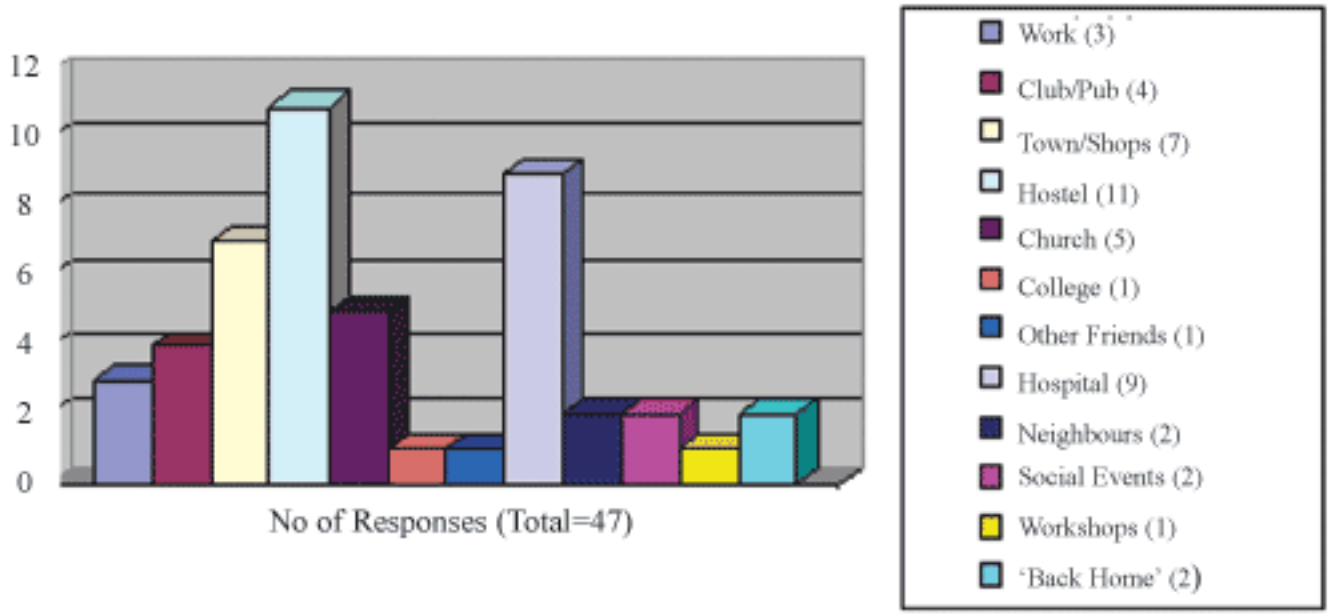


Chart 8. The Different Places the Women met their Friends

- 37% of the women said they had problems having a social life.

- 25% of these women related some of their problems having a social life back to their HIV positive status.

'people look at me differently because of my sickness'

'I do not feel free because I don't want them to know that I'm positive'.

- Other problems/barriers to having a social life included having no one to take care of children, being depressed, a fear of rejection and language barriers

'I can't speak English very well and this is a big problem'.

The women in the research group were clear that their HIV positive status had made having a social life more difficult for them because they were fearful of others finding out about their status, which in turn made them wary of strangers. Many had experienced very hostile reactions from friends, and family, in the past when they told them about being HIV positive.

The women in the research group agreed that the Women's Support Group had been good for them because if was one of the few (if only) safe spaces where they did not have to expend any energy or indeed worry about their status becoming known because everyone there was in 'the same boat'.

3.3.12 Spiritual Life

- 96% of the women stated that they had spiritual beliefs

Table 11. The Types of Spiritual Beliefs held by the Women

The Type of Beliefs/Faiths	No of Women	% of the total
Christian	24	51%
A belief in God	10	20%
A belief in Jesus Christ	4	8%
Catholic	3	5.5%
Muslin	3	5.5%
Protestant	2	4%
A belief in Ancestral Spirits	1	2%
Not answered	2	4%

- 86% of the women stated that they receive spiritual support in Ireland; just over half (55%) were receiving this support from the church, 4% from their friends and 4% from their husbands.
- 80% of the women were happy with the spiritual support that they receive.

The majority of the women in the research group had strong spiritual beliefs and many attended regular religious services. The majority of the women were of the opinion however, that if their status was to become known within some of their churches that they would not be welcome anymore. This was a source of significant stress for the women.

3.3.13 Support Organisations

- Half of the women (50%) knew about at least one support organisation.
- The support organisations named by the women were Open Heart House (16%), Cáirde (10%), Grandma's Ireland (4%) and St. Vincent De Paul (4%).
- 39% of the women had had direct contact with one or more support organisations
- 79% of the women who had had direct contact with a support agency/agencies described this as a positive experience.
- 16% of the women described themselves as having been directly involved in one/or more of the support organisations. Involvement generally took the form of attending meetings, socialising and using the organisations as a regular source of advice and support.

The Next Section

The next section highlights the key issues emerging from the research based on discussions of these findings with the research group who identified a number of specific issues and themes which emerged as being of central importance to the quality of life of women living with HIV.

Part 4. Issues Emerging for Minority

4.1 Introduction

The findings of this research relate specifically to African women living with HIV who came to live in Ireland over the last seven years. These findings were in turn discussed and analysed in ongoing focus group discussions with the research group and the wider Women's Support and Development Group. The findings and ongoing focus group discussions highlighted a number of key issues. These issues, while particularly pertinent to African women living with HIV in Ireland, may have a wider resonance and relevance to the wider constituency of other minority ethnic women living with HIV in Ireland.

The women in this study came to Ireland because of major problems in their home countries, including poverty, war, and other problems. Some of the women feel traumatised by events witnessed in their own countries and are dealing with these issues in Ireland. These women want to work and want to study, but in many cases are not allowed to do so. This section summarises the key issues emerging from the interviews and the focus group discussions.

4.2 Legal Status

It emerged through the process that there is a lack of clarity among some women about their legal status in Ireland, and consequently a lack of clarity about their rights and entitlements in Ireland. Processes to ensure the right to stay in Ireland either through the asylum process, work permits, student visas or other means, are a source of great anxiety and stress. It also emerged that the legal status of a woman is the key to accessing services, and it appears that many women whose entitlement is unclear find themselves accessing services on an ad hoc basis.

4.2.1 Asylum Process

The women indicated many negative aspects to the asylum process, particularly the system of dispersal and direct provision, as summarised below.

Many of the women's experience of the asylum process was slow; some women in this study had been in the process for years.

Right to Work

Asylum seekers are not allowed to work. Many of the women therefore found themselves doing nothing for periods of time, effectively putting their lives on hold, which was demoralising. This is significant given that many of them had transferable and useful employment skills.

Dispersal and Direct Provision

The dispersal and direct provision system was difficult for this group of women for a number of reasons. The majority of women living with HIV prefer to keep their HIV status confidential. Shared accommodation makes this particularly difficult due to the need for regular medication and for the refrigeration of some medication. Women are fearful of being asked questions about why they are taking medication, why are they not breastfeeding etc. Women experience difficulty disguising these aspects of their lives in communal living, and sometimes find it difficult to adhere to a strict medication regime if for some reason they cannot take their medication at the appropriate time e.g. someone in the room at the time. Women living with HIV need access to cooking facilities in order to ensure they get the balanced healthy diet. This is not possible in direct provision accommodation.

The dispersal of people around the country means some women may be located far from specialist clinics, which are located in Dublin, Cork and Limerick.

In addition, women had concerns about the possibility of the transfer of air-borne infections, which may be a particular risk for women with suppressed immune systems. In order to leave the direct provision system many of the women had to disclose their HIV status to people other than medical professionals or those involved in assessing their asylum applications. More recently this has become even more difficult due to the introduction of a policy of almost exclusive direct provision of all newly arriving asylum seekers, who will no longer have the option of seeking other types of accommodation, even on medical grounds (only in circumstances of extreme medical need).

Not all the women had a good knowledge of English when they arrived in Ireland and this put them at a disadvantage in terms of negotiating the asylum process and assimilating into the wider community at a later stage.

4.3 Money & Employment

The women in this study have great difficulty making ends meet, and accessing jobs to supplement income or replace social welfare is also extremely difficult, for reasons set out below.

These women are generally dependent on social welfare payments for their income.

The payments made to asylum seekers in direct provision are inadequate to cover the costs of nappies, additional milk, clothes and other items necessary when bringing up children.

However, women find they cannot access the jobs market: those who are asylum seekers are not allowed to work; for others there is a lack of affordable childcare in order to take up employment; in many cases, their qualifications are not recognised in Ireland; some indicate that periods of ill health prevent them from holding down employment; and poor English can be a significant barrier to taking up employment.

There are no employment stepping stones. If employment is taken up, social welfare entitlements are lost and for many, losing these payments immediately can be too difficult. Also, health needs of women living with HIV, and medication and appointment regimes indicate that flexible employment would be required if women are to be supported to take up employment (see Health below).

4.4 Education and Training

The women in the study had a broad range of skills and occupations, with many of the women having qualifications and skills that could be used in Ireland. Furthermore, many of the women are keen to undertake further education and training (particularly computer training).

However, barriers to accessing education and training are similar to those regarding employment outlined above. Asylum seekers do not have access to government training initiatives and previous training/qualifications are sometimes not recognised. Many women are frustrated at losing time doing "nothing" while waiting for asylum applications to be processed, rather than training during this period. Also, some recentlypositive women have been advised to re-train as their HIV positive status is considered high risk in their profession. A poor level of English is an additional difficulty for some women.

4.5 Health

In terms of health, many of the women in this research feel generally unwell. This is a very important point, as it has implications for design of any services targeted at women living with HIV.
Most women were diagnosed positive when they decided to opt for voluntary health screening on their arrival in Ireland. After the initial shock of the 'positive test' the women generally thought it was better to know, particularly where there was a chance that they might have children in the future. They feel it is also better to know because of the availability of medication in Ireland, which would enable them to manage their infection and general health in a more structured way.

Most women visit their GP and have regular check-ups. There remained however, a significant number who did neither, which is worrying given the importance of maintaining ones general health level when you are HIV positive.

Taking HIV medication, and regular visits to the specialist clinics, are a significant part of most of the women's lives, and these have to be factored in to organising their routines.

Women spend significant lengths of time in waiting rooms at specialised clinics. This causes frustration, and also some fears as a woman's risk of being exposed as being HIV positive is increased by the amount of time she has to spend in waiting rooms at specialised clinics.

The absence of appointment systems within the hospitals, and poor-time keeping where there were appointment systems, was the cause of significant levels of stress for the women, particularly in terms of childcare and time off from work. However, women were generally satisfied with the level of service at specialised clinics.

4.6 Accommodation

The women want to live in private accommodation where they can have privacy and space. They do not want to live in hostel or communal type accommodation. However, as with other groups, the accommodation crisis in Dublin has caused many problems for the women. These include great difficulty in finding accommodation within community welfare rent limits or experiencing racism from some potential landlords. Given the location of specialist clinics in Dublin, many women would find it very difficult to live in rented accommodation in rural towns where rent is may be more affordable due to having to travel to Dublin for treatment and check ups.

4.7 Family Support

Bringing up children in Ireland is a challenging task for the women given the absence of wider family support and cultural differences in terms of discipline and parental expectations of their children.
The lack of affordable childcare was a cause of significant stress particularly where they had to attend hospital clinics on a regular basis. The women generally do not have access to emergency or overnight childcare should they become ill, have to give birth or indeed if their general health status deteriorates rapidly.

Childcare is a particular concern for HIV positive women. This is even more so if their children are also positive, where childcare providers would require a good understanding of HIV and the medication regime.

4.8 Racism

These women experience racism. They experience various forms of racism, more commonly racist comments on the street, with some incidents of physical assault. A significant amount of racist comments were made within the context of public service provision (e.g. the bus or the Social Welfare offices) by staff and customers/client alike, and this was the cause of significant stress and distress for the women.

4.9 Personal Lives

4.9.1 Relationships

The disclosure by a positive woman of her HIV status in relationships with partners is a very difficult issue and it is something that many women struggle with even within their most intimate relationships. Experiences of informing partners have often been very hostile and negative; and women have indicated that they have not received any support in coming to terms with this. Honesty, trust and an understanding of HIV were the characteristics most valued and most needed by minority ethnic women living with HIV. Significant numbers of those surveyed living with HIV would appear to be in what might be termed 'unhappy' or 'unsatisfying' relationships, with a lack of understanding of HIV cited as the major factor in this. The majority of women practice safe sex. However, there are some women who do not, or are not in a position to practice safe sex.

4.9.2 Social Life

Women living with HIV are very wary of disclosing their positive status, due to negative experiences in the past, or a fear of a negative reaction. Therefore, many positive women reduce this risk by keeping others at arms length, leaving them socially isolated. Financial survival is a constant struggle for the women and the women's social life is constricted as a result of this struggle. Positive women tend to make friends with other women in similar situations. The majority of women met and made their friends through their time in a hostel or through attendance at hospital. The opportunity for the women to make Irish friends is limited by the fact they generally do not work and often live in restricted accommodation, and as such have little opportunity (time or money) to meet others outside of their regular routines (in the hospital, clinics or churches).

4.9.3 Spiritual Life

Spirituality and faith are strong elements of many of these women's lives, and many of the women draw significant support from their churches. However, the women feel that some churches and religions are intolerant of individuals who have contracted diseases like HIV, and the women are generally wary of disclosing their status to either church elders or other church members.

4.9.4 Support Organisations

Many women are not linked in with the range of support organisations and advocacy groups. Many were unaware of the different support organisations that exist; in that they did not have information about the range of organisations for minority ethnic women , or the range of organisations for those living with HIV.

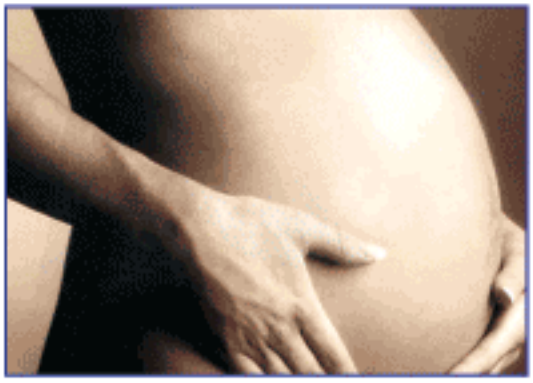
The women who had linked with HIV sup organisations were generally happy with supports they received. The women used e support organisations primarily as a source of information and support. Many also recognised these organisations as a safe venue for socialising with other women in similar situations.

Part 5. Recommendations.

5.1 Introduction

This section recommends some changes which would positively impact on the lives of women living with HIV. If implemented, many of these changes would facilitate minority ethnic women living with HIV to lead fulfilling lives, and would support them to become part of Irish society, rather than living silently on the fringes.

Cairde will support the Women's Support and Development Group to meet with policy makers in an effort to have changes introduced, and will facilitate the Group to develop supports for other women living with HIV. The Action Plan in the next section sets out the framework of the Women's Support and Development Group to achieve this.



5.2 Key Recommendations

Recommendation 1: Amend the Asylum Process
Recommendation 2: Improve Access to Employment Opportunities
Recommendation 3: Facilitate Access to Education & Training Opportunities
Recommendation 4: Improve Access to Health Services
Recommendation 5: Improve Access to Accommodation
Recommendation 6: Provide Support Services & Family Support
Recommendation 7: Tackle Racism and Promote Interculturalism

Recommendation 1: Amend the Asylum Process

Recommendation	Body Responsible
Reduce the time for processing asylum applications to six months or less.	Office of the Refugee Applications Commissioner;(ORAC)Refugee Appeals Tribunal (RAT).
End the Direct Provision and Dispersal System and integrate asylum seekers back into mainstream social and supplementary welfare systems.	Dept. Justice, Equality & Law Reform (DJELR).
Until such a time as the Direct Provision and Dispersal System is ended, review the suitability of direct shared accommodation for HIV positive women with a view of reintroducing the scheme of allowing HIV positive women access private rented accommodation on medical grounds.	Reception and Integration Agency (RIA).
Increase the weekly allowance to asylum seeker families in direct provision comparable to mainstream unemployment allowances and social benefits.	DJELR, Department of Social and Family Affairs (DSFA).
Provide properly trained interpreters for all discussions regarding asylum applications.	RIA.
Increase resources for the provision of English languages classes free of charge to asylum seekers throughout the country to increase number of teachers and increase availability of classes.	RIA & Dept Education & Science
Improve information materials for women about their rights and entitlements and put in place a dissemination strategy to get this information to women in their local communities.	RIA, Cairde, Other Local Groups.

Recommendation 2: Improve Access to Employment Opportunities

Recommendation	Body Responsible
Allow asylum seekers to take up employment if after a period of six months they are still within the asylum process.	DJELR.
Assess and review current systems for the recognition of qualifications from other countries, and develop a mechanism to support people to have qualifications recognised.	Dept. Enterprise, Trade & Employment, Dep.Education & Science, IBEC, ICTU.
Provide women with living with HIV with information about employment support services available for those who are seeking work.	Cairde & WS&DG.
Provide training to employment support services about the needs of minority ethnic women and the needs of women living with HIV.	NCCRI, Cairde & WS&DG.
Review the disability allowance scheme; and develop a flexible social welfare mechanism to provide greater financial security to women living with HIV, who may experience fluctuating periods of employment due to ill health.	DSFA.
Re-introduce allowances and schemes which facilitate the gradual withdrawal of social welfare entitlements upon gaining employment.	DSFA.
Review the work permit and working visa systems to explore levels of protection and exploitation experienced by workers; and amend the system to ensure greater protection of workers by allowing employee to hold the work permit rather than the employer.	Dept. Enterprise, Trade & Employment, Department of Justice - Immigration Division.
Public services should actively recruit members of minority ethnic communities. The gender strategy for the public service needs to reflect the inclusion of minority ethnic women.	All public services.

Recommendation 3: Facilitate Access to Education & Training Opportunities

Recommendation	Body Responsible
Provide women living with HIV with information about employment support services available for those allowed to access training.	Cairde & WS&DG.
Allow asylum seekers to take up FAS and State funded training initiatives, if after a period of six months they are still within the asylum process.	DJELR, FAS, Department of Education & Science (DES).
Provide English language training for minority ethnic women and their families.	DJELR, FAS, DES and Local Community Groups
Provide affordable childcare to those in training courses, as is the case in circumstances of exceptional need.	FAS and DES.
Ensure that community based education opportunities are targeted at and made accessible to minority ethnic women.	FAS, DES and Local Community Groups

Recommendation 4: Improve Access to Health Services

Recommendation	Body Responsible
Develop culturally appropriate materials to encourage women to take a HIV test; including information about the benefits of early diagnosis of HIV, availability of HIV treatments, location of HIV testing and treatment centres, availability of follow-up counselling services and HIV related information. Develop these materials in partnership with women living with HIV.	ERHA, Cairde, WS&DG, RIA and Hospitals
Review current appointments systems in consultation with service users, and introduce and maintain an efficient appointment system for attendance at the specialised HIV clinics.	ERHA and Hospitals

Provide drop-in crèche facilities at HIV clinics.	ERHA and Hospitals.
Maintain current confidentiality systems at HIV specialist clinics.	ERHA and Hospitals.
Inform people living with HIV about additional allowances to which they may be entitled.	ERHA, Cairde and Hospitals.
Provide all people living with HIV with medical cards.	ERHA and Dept Health & Children.
Review accessibility of GPs through the GMS, and develop a mechanism to address difficulties in getting accepted on to GP lists.	ERHA and Dept Health & Children.
Review barriers to women attending GP regularly, and in partnership with people living with HIV look at how this can be addressed.	ERHA and Dept Health & Children.
Provide GPs with training regarding HIV and issues affecting minority ethnic women, with the participation of people living with HIV, minority ethnic women and their community organisations.	ERHA, ICGP, NCCRI, Cairde and WS&DG.
Provide interpreters at hospitals, GPs and other health services for those who do not speak English.	ERHA and Dept of Health.
Provide locally based counselling services to those diagnosed with HIV to support them to come to terms with a HIV positive diagnosis. (through Community Care or through new Primary Care)	ERHA.
Develop a culturally appropriate sexual health and safe sex strategy in consultation with, and the participation of minority ethnic communities and organisations.	ERHA and Health Promotion Units.
Put in place supports for undocumented women who are in need of maternity care and emergency health services.	ERHA and Dept. Health & Children.

Recommendation 5: Provide Access to Accommodation

Recommendation	Body Responsible
Establish a body to mediate between tenants and landlords.	Dept. of EnvironmentDublin City Council
Establish a body to whom complaints can be made about illegal or irregular practices among landlords.	Dept. of EnvironmentDublin City Council
Increase rent allowances to people living with HIV when necessary to ensure that they can access rented accommodation.	ERHA

Recommendation 6: Provide Support Services & Family Support

Recommendation	Body Responsible
<u>Counselling Supports</u> Increase resources for culturally appropriate counselling services to those who have witnessed incidents and/or lost relatives/friends in conflicts in their own countries to reduce waiting lists for such services.	ERHA.
Provide locally based counselling services to those diagnosed with HIV to support them to come to terms with a HIV positive diagnosis. (through Community Care or through new Primary Care) Repeated from Health Section.	ERHA and Hospitals.
Provide relationship support and counselling to couples coming to terms with a HIV diagnosis for one or both partners.	ERHA and Hospitals.
Provide information for the partners of HIV positive women to improve their understanding and knowledge of HIV.	ERHA, Hospitals, Cairde and WS& DG
Provide training to counsellors on HIV and the experiences of ethnic minorities; in partnership with minority ethnic women and women living with HIV.	ERHA, NCCRI, Cairde and WS& DG.

Childcare & Family Support Provide affordable childcare for women living with HIV taking up training and/or employment opportunities.	ERHA
Make short-term respite and/or residential type child-care available for such instances of hospital stays or periods of illness.	ERHA
Provide crèche facilities at the specialist clinics where women attend.	ERHA and Hospitals
Allow family reunification to enable women to benefit from family support.	Immigration Division at Dept. Justice
Community Supports Provide funding for personal development and related courses to enable HIV positive women develop greater levels of self esteem and confidence.	ERHA & Dept. Health & Children
Provide funding for community development with women living with HIV to address their difficulties.	ERHA & RIA & Dept. Health & Children Dept. Community, Rural and Gaeltacht Affairs
Promote greater awareness among minority ethnic communities of the variety of community and support organisations which can assist them.	Cairde
Promote greater awareness among minority ethnic women living with HIV of the various specialist support organisations that exist and the services and supports that each provide.	Cairde & ERHA & RIA
Church Support Provide information to churches about HIV to facilitate greater understanding of the issues affecting people living with HIV.	Cairde & WS&DG
Encourage and support churches to take on a proactive role in addressing stigma experienced by people living with HIV.	Cairde & WS& DG

Part 6. Action Plan

2003-2004

Women's Support & Development Group will meet regularly, facilitated by Cáirde, so that ethnic minority women living with HIV have somewhere safe to come together.

Accommodation:

- Meet with ERHA and Dublin City Council to explain difficulties with accommodation and rent allowances.

Racism:

- Send the Report to NCCRI and Equality Authority.
- Invite Equality Authority to meet with WS&DG.
- Design a leaflet giving other women information about what to do if they are subjected to racism or discrimination.

Lobbying:

- Send report to Dept of Justice, RAC Immigration Division, RIA, Dept. of Health, NASC, Health Professionals, NCCRI ERHA, Dublin City Council etc.
- Seek a meeting with relevant officials in Gov. departments.
- Seek a meeting with politicians who can influence policy.
- Attend Events organised by other groups such as NWCI, AKIDWA, NCCRI etc.

Supports:

- Meet with ERHA to talk about improving supports to women such as child care, counselling etc.

Education, Training & Employment:

- Invite FAS, FETAC, Local Employment Service to meet with WS& DG to explore training and employment options of group members.
- Organise computer training for WS&DG members.

Health & HIV:

- Design a leaflet to help other women who have not yet taken a HIV test, the leaflet will show the experiences of testing positive, benefits of knowing. Access to treatment in Ireland etc.
- Seek a meeting with officials in Dept of Health & Children and NASC to highlight difficulties.

Personal Lives:

- Conduct a storytelling project where each member of the group tells her own story. It could be written stories, recorded stories, photo or sculpture. The group will decide the method. The stories will be published or exhibited so the public can hear the real stories of women.
- Design a leaflet to help other women living with HIV in their personal relationships, how to tell a partner how to tell our children.
- Attend events organised by other groups, AKIDWA, ICON etc.

Information:

- Design a leaflet for other women about legal status and explain to them what they are entitled to in all services and how to get them. Especially accommodation, social & supplementary welfare allowances, health & HIV services, legal services and other supports. It will include how to make a complaint if you're not getting what you're entitled to

Asylum:

- Organise open meeting for women living with HIV to provide information about the asylum process, Supreme court ruling and other related information.
- Seek a meeting with Dept of Justice officials in relevant sections to highlight difficulties with Dispersal and Direct Provision.
- Seek a meeting with politicians who may influence policy in Dept of Justice.

Part 7.Appendices.

Appendix 1. Some Key Figures from the National Disease Surveillance Centre

Year	2000	2001	2002 (Jan-June only)
Total New Reported Diagnoses	290	299	157
Year Total New Reported Diagnoses % of new HIV infections among women	40% 116 women	45% 134 women	62% 97 women
% of new infections through heterosexual contact	44% 127 people	58% 173 people	70% 110 people
% of women among new HIV infections through heterosexual contact	65% 83 women	66% 114 women	78% 86 women
% of new infections through intravenous drug use	29% 83 people	3% 38 people	9 % 14 people
% of women among new HIV infections through intravenous drug use	36% 30 women	29% 11 women	42% 6 women
% of total cases resident in the Eastern Regional Health Authority	76% 220 people	62% 185 people	70% 110 people

Survey of Women from Different Cultural Backgrounds Experiences of Living in Ireland.

We are putting together a picture of the experiences and needs of Women from Different Cultural Backgrounds who are living in Ireland. We would be grateful if you would help your interviewer complete this questionnaire. The questionnaire is anonymous and any information you give will be treated in the strictest of confidence.

1 Cultural Identity

1.1 Where are you from originally? _____

1.2 What is your status in Ireland? _____

1.3 How long have you been in Ireland?
☐☐ years or ☐☐ months ☐☐ 1.4 Age? ☐☐ years

1.5 Why did you come to Ireland? _____

_____

_____

_____

1.6 What have you been doing since you came to Ireland? _____

_____

_____

_____

2. Living Space and Safety

2.1 Where do you currently live?
Town/Area _____ City/County _____

2.2 Where did you live when you first came to Ireland (if different from Q 2.1)?
Town/Area _____ City/County _____

2.3 What type of accommodation do you live in now?

✓ one

- ☐ Public Housing
- ☐ Private Rented Accommodation
- ☐ Own Home

✓ one

- ☐ Hostel
- ☐ B&B
- ☐ Hotel
- ☐ Apartment/Flat
- ☐ Room in shared Apartment/House
- ☐ Other (please speciy) _____

2.4 Are you happy with your accommodation? ✓only one ☐ Yes ☐ No
Explain why? _____

_____

_____

_____

2.5 Do you feel safe living in Ireland? ✓only one ☐Yes ☐No
Explain why? _____

_____

_____

_____

2.6 Have you ever experienced any racism
since you have been in Ireland? ☐ Yes ☐ No

If Yes what type? _____

_____

_____

_____

3. Family

3.1 Have you family here in Ireland? ☐Yes ☐No
(if Yes complete the remainder of the question if no move to Q. 3.2)

Tick/Number

☐ Husband/Partner
☐ Children Boys ☐☐ Ages ☐☐ ☐☐ ☐☐ ☐☐ ☐☐
Girls ☐☐ Ages ☐☐ ☐☐ ☐☐ ☐☐ ☐☐
☐ Brothers /Sisters
☐ Parents
☐ Cousins
☐ Uncles/Aunts

3.2 What is it like bringing up children in Ireland/is it different in your country?

_____

_____

_____

3.3 How do you manage for childcare? _____

_____

_____

_____

4. Health

4.1 Are you a healthy person generally? Yes ☐ No ☐

4.2 How often do you visit your G.P/Doctor ✓ one
☐ Weekly ☐ Fortnightly
☐ Monthly ☐ Occasionally
☐ Never

4.3 Do often do you have check-ups? ✓ one?
☐ Weekly? ☐ Fortnightly
☐ Monthly ☐ Occasionally
☐ Never

4.4 Do you take any medication? ☐ Yes ☐ No
(if yes)
What kind? _____

4.5 How is the medication for you? _____

4.6 How often do you go to the hospital? ✓ one
☐ Weekly? ☐ Fortnightly
☐ Monthly
☐ Every three months
☐ Occasionally
☐ Never

4.7 How do you manage going to the hospital? _____

_____

_____

_____

4.8 In general how do you find the Health Service/Accessing the Health Service in Ireland ? _____

_____

_____

_____

5. Relationships

5.1 Are you in a relationship at the moment?
☐ Yes (if yes go to Q 5.2)
☐ No (if no go to Q 5.6)

5.2 How long have you been together?
☐☐ years or ☐☐ months or ☐☐ days

5.3 How would you classify your relationship
(a marriage/a boyfriend/a long term partner) _____

5.4 What are the things you like about your relationship? _____

_____

5.5 Are you fully open and honest with you partner ☐ Yes ☐ No

5.6 What do you/would you want from your/a relationship? _____

_____

_____

_____

5.7 Are you currently sexually active? ☐ Yes ☐ No

5.8 Do you/would you practice safe sex? ☐ Yes ☐ No

Employment and Money

6.1 Do you work? ☐ Yes ☐ No
Explain Why: _____

If yes do you work Part-time or Full-time? ✓ only one ☐ Part-time ☐ Full-time

How long are you in your current job? ☐☐ years or ☐☐ months

What is your current job? _____

Do you like your present job? ☐ Yes ☐ No

Explain Why: _____

6.2 What was your main occupation in your home country? _____

6.3 Are you currently seeking work? ☐ Yes ☐ No
Further details: _____

6.4 How do you manage financially? _____

_____

_____

_____

7. Social Life

7.1 What do you do /would you like to do in your spare time? _____

_____

_____

_____

7.2 Do you have friends here? ☐ Yes ☐ No
If yes how did you meet them?

7.3 Do you have problems having a social life? ☐ Yes ☐ No

If yes what kind of problems? _____

_____

_____

_____

8. Education and Training

8.1 What is the highest level of education you have completed to date? üonly one

☐ Primary education ☐ Lower secondary
☐ Upper Secondary ☐ Technical or Vocational
☐ University

8.2 Can you use your qualifications in Ireland? Yes☐ No ☐

Explain Why? _____

_____

_____

_____

8.3 Are you currently studying? ☐ Yes ☐ No
(if no go to Q 8.5)

8.4 Where and what are you currently studying?
Where? _____ What? _____

8.5 Would you like to do any further studies/training? ? ☐ Yes ☐ No
if yes What? _____

9. Spiritual Life

9.1 Do you have any spiritual beliefs? ☐ Yes ☐ No
if yes What kind? _____

9.2 Do you get any spiritual support? ☐ Yes ☐ No
if yes from Whom? _____
Are you happy with this support? _____

10 Support Organisations

10.1 What support organisations do you know about? _____

_____

_____

_____

10.2 Have you had any contact with any of these agencies, ☐ Yes ☐ No
What organisations? _____
What was your experience like? _____

10.3 Are you directly involved in any support organisations? ☐ Yes ☐ No
if yes?
What does your participation involve? _____

_____

_____

_____

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Some Useful Websites

Dept of Justice, Equality and Law Reform: www.justice.ie/

Irish Council for Civil Liberties: www.iccl.ie

Irish Refugee Council: www.irishrefugeecouncil.ie/

National Disease Surveillance Centre - www.ndsc.ie/Disease Topics A-Z/HIVandAIDS/

Dept of Foreign Affairs: www.irlgov.ie/iveagh/

Reflections.

A lot of people have put a lot of work into preparing this report. The research participants in particular have put a lot of themselves into this work. It would be a crying shame if this report were allowed to gather dust. It is all our fervent hope that this report will be used as a basis for future action.

When I tell my partner that I am H.I.V. positive, he was too much confused, upset, hopeless, miserable-not seeing a future between us.

On a droit de vivrne comme tout les monde malgrne le H.I.V.

I am H.I.V. positive but I am still happy and enjoying my life to the fullest, like everyone else, positive and live a positive life.

If I am H.I.V. positive it doesn't mean I cannot bear children. The children are treated as well. But I thought it was happening to me only. Look, now I am happy and healthy because I am on medication.

Je crois qui'étant consciente de ma maladie, J'ai realise que jai besoin d'un support, et partage familia quimporte ma seropositive, mes amis restent, et demeurent mes seuls partenaires de reconfort.

Mavoto,Masuzgo, Makamb, Wahala, Help Us!

Cáirde

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